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ABSTRACT

One of the desired outcomes of transition planning for students with disabilities is to enable the students to lead a quality adult life. This report contains a literature review which outlines recent approaches to addressing quality of life issues, including conceptualizations, methodologies, and ethical concerns. A field inquiry report summarizes the results of interviews conducted among individuals with disabilities. These interviews were conducted with 45 persons, ranging in age from 20 to 50. Eight domains were explored during the interviews, including: environment, employment/occupation, education/training, health, community utilization, personal management, leisure/recreation, and interpersonal relations. Three domains were mentioned repeatedly as areas needing improvement or contributing to negative experiences/feelings. These three domains were: interpersonal relations, environment, and community utilization. Based on information from the literature review and interviews, a definition of quality adult life is presented as a working model. A copy of the form used to guide the interviews concludes the document. (JDD)

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# **Quality of Life for Individuals With Disabilities:**

A Conceptual Framework

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## INTRODUCTION

This paper has been developed in response to the recent emphasis on transition policy and planning for students with disabilities. A chief outcome of successful transition for these students is the ability to lead a quality adult life. A number of questions arise from this basic premise. What constitutes a quality adult life? What factors enable a person to achieve it? Is quality of life the same for disabled and non-disabled? How can it best be measured? How can parents, care providers, educators, and communities best prepare these students to achieve a high quality of life as they enter adulthood? What are the ethical issues to be addressed? It is imperative that these questions be answered, and that the answers serve to guide both policy makers and practitioners as they seek to evaluate and improve the transition process.

The paper is divided into three sections. A literature review outlines recent approaches to addressing quality of life issues, including conceptualizations, methodologies, and ethical concerns. A field inquiry report summarizes the results of interviews conducted among individuals with disabilities. Finally, a definition of quality adult life is presented as a working model to inform present practice and to guide future research efforts.

## Part I

### LITERATURE REVIEW

Quality Of Life (QOL) research has expanded greatly in recent years. This review includes only a small portion of currently available information on the subject. It does, however, reflect a broad-based sampling of recent theory and practice from a wide variety of disciplines. It is within this breadth of information that a useful framework for viewing and evaluating quality adult life as a transition outcome for students with disabilities can begin to emerge.

#### Summary of Existing Global Definitions

In moving toward a framework for understanding QOL, it is helpful to consider how it previously has been defined as a global construct, and how these definitions have been supported by other research. Rice (1984) views QOL as the degree to which the experience of life satisfies a person's wants and needs, both physical and psychological. Other researchers concur that when most people conceptualize QOL they think in terms of life satisfaction (Dalkey & Rourke, 1973; Ferrans & Powers, 1985; Møller & Schlemmer, 1983). There seems to be a distinction, though, between satisfaction and happiness. Campbell et al. (1976) suggest that satisfaction is a cognitive dimension, while happiness is grounded in affect. This distinction is partly supported by Andrews & McKennell (1980), who found that measures of happiness contained higher affective content than measures of satisfaction. Both components, say Campbell et al., are included in QOL. They also contend that the two do not always correlate highly.

Milbraith (1982) defines QOL as an outcome that results from personal values and from lifestyles that attempt to fulfill those values. These lifestyles, according to Reich and Zautra (1983), also represent the interaction between a person's desires and the outside demands placed on the person. This perspective is supported by Mastekaasa and Moum (1984), who suggest that ideal QOL is a state of harmony between person and environment. QOL is optimal, they say, when individual needs are in balance with societal supplies, and when environmental demands are in balance with individual resources. This social-ecological perspective, where the person-environment transactions yield the QOL experience, has become increasingly salient in QOL research (Bubolz et al., 1980; Russell & Ward, 1982; Shin et al., 1983).

To summarize, global definitions of QOL seem to focus on life satisfaction, personal happiness, and the individual-environment match. It is within these broad areas that QOL research and evaluation has found much of its direction. As the field continues to refine its methods, more insight will be gained into these areas and into new ways of conceptualizing life quality.

### Psychological and Interpersonal Factors

A number of psychological and interpersonal factors are believed to be associated with QOL. Since self-esteem is foundational to psychosocial health, it is often associated with QOL. Campbell (1981) reports a high correlation between levels of self-esteem and overall life satisfaction. Other studies corroborate this relationship, suggesting that self-esteem is an important moderator of life experience and perception of life quality (Gecas, 1982; O'Connor & Brown, 1984; Pearlin et al., 1981). In evaluating personality traits and QOL, Heady et al. (1985) identified self-esteem and personal competence as the two major influences on perceptions of well-being. In a study of the psychological mediators of the experience of arthritis, Burckhardt (1985) found a high regard for self as the strongest single factor in effective adjustment to the disability.

Another psychological factor that seems to relate to QOL is a feeling of manageability or control over one's life (Abbey & Andrews, 1985; Margalit & Cassel-Seidenman, 1987). Some of these studies show that internal locus of control correlates highly with a high QOL, while others have found positive perceptions of life quality even among those with external loci of control. While there are these discrepancies, it does appear that the feeling of being able to manage one's own life is an important contributor to QOL. In a study of QOL among the elderly, Taft (1985) found a loss of control over their environment to be a significant barrier to high QOL. In another study, Deiner (1984) reports a sense of environmental control as a strong predictor of feelings of well-being.

In an extensive investigation of sociological perspectives on QOL, Schuessler and Fisher (1985) concluded that overall QOL is most closely associated with interpersonal relationships at the primary group level. Baird (1985) supports this line of thought by suggesting that the quality of one's relationships forms the foundation for a meaningful life. Zautra (1983) expands upon the interpersonal area, reporting that both the availability and the quality of interpersonal relationships are significant contributors to life satisfaction. He suggests, too, that when most people think about QOL, they find their ties to others emerging as one of the most important dimensions.

A number of other researchers similarly contend that social interaction and social support are essential for good QOL (Abbey & Andrews, 1985; Gecas, 1982; Taft, 1985). Brown and Harris (1978)

assert that the ability to confide in others is a major concomitant of good mental health and effective stress management, both of which contribute to high QOL.

It is evident that psychological and interpersonal dimensions play an important role in the study and improvement of QOL. In juxtaposing the two dimensions, it becomes apparent that QOL is at once a personal experience and a construct that is always embedded in social structure and processes.

### Disabled vs. Non-disabled

A recent poll (Harris, 1985) reveals that persons with disabilities believe themselves to be better off than they were ten years ago. Nonetheless, the same poll reports that, by comparison to the non-disabled, individuals with disabilities are poorer, less educated, and less able to access employment and other areas that interest them. Less than 40% acknowledge involvement in community life. Clearly, there is still plenty of room for improvement in equal opportunity.

It might be presumed from such a poll that the life quality of many persons with disabilities is lower than the life quality of the non-disabled. Yet Weinberg (1985) found no significant difference in reported life satisfaction between the two groups. His results are corroborated by Stensman (1985), who found that many functions lacked by the disabled were less important to them and therefore did not substantially lower their life satisfaction.

Employment has been a long-standing matter for concern among persons with disabilities. The aforementioned Harris poll found that disabled persons who are working tend to see themselves as less disabled than similar persons who are not working. Yet employment does not always correlate with QOL. Brief and Hollenbeck (1985) found that job satisfaction has little to do with overall contentment with life. Similarly, Murrell et al. (1983) report that being employed does not necessarily improve perceived QOL. It is plausible that while employment is important in normalization of the disabled, and in bringing them to a minimum standard of living, it is by no means the most important criterion for achieving high QOL.

The QOL differences between disabled and non-disabled persons appear to fall in a gray area where generalizations really cannot be made. Nonetheless, there is a growing need to examine QOL issues in relation to transition planning for young people with disabilities. In one recent study, disabled students judged the importance of the training they had received in school. They rated social skills, independent living, and the use of leisure time as far more valuable to them than academic programs (Margalit & Cassel-Seidenman, 1987). Social isolation and lack of community integration remain a problem for many disabled youth and adults. Schalock & Lilley (1986) state that disabled individuals in community-based

programs reported high levels of QOL only when their jobs and living arrangements remained fairly stable over a period of time, giving them an opportunity to establish strong social ties.

Turnbull and Turnbull (1985) offer perhaps the most cogent analysis of the direction needed for transition strategies that address QOL issues. They contend that access to life experience is often limited for youth with disabilities. It is this life experience that underlies the ability to make choices, and it is these choices that often determine the level of life quality. QOL evaluation, and subsequent strategies for improvement of QOL outcomes, must in some way focus on teaching disabled students how to make, communicate, implement, and evaluate their own life choices.

### Measurement of QOL

Systematic evaluation of QOL is a difficult task in which true precision is probably never attainable. As Schuessler & Fisher (1985) point out, QOL is a latent trait that is not subject to direct measurement. Many researchers have discussed the highly individual nature of QOL, suggesting that personal goals and values always confound the measurement process (George & Bearon, 1980; Landesman, 1986; Rice, 1984). Other researchers emphasize the affective component of QOL, stressing that feelings and subjective perceptions are not always readily measurable (Campbell, 1981; Crandall & Putman, 1980). Most QOL studies, however, use various types of subjective data (Andrews & Withey, 1976; Bortner & Hultsch, 1970; Kazak & Linney, 1983), based on the belief that purely objective information is inadequate.

There has been considerable controversy over objective vs. subjective indicators of QOL. Rice (1984) distinguishes between objective QOL and perceived QOL, the former being based on specified standards of living and the latter representing affective beliefs directed towards one's life. A number of researchers have found that objective indicators do not correlate well with subjective measures of life satisfaction (Henderson et al., 1981; Milbraith, 1982; Sarason et al., 1983; Schneider, 1976). According to Møller and Schlemmer (1983), the real value in QOL research lies in the subjective area. They do admit, though, that objective indicators have a place in the research, since objective conditions often impact the subjective experience of individuals.

In actual practice, both objective and subjective assessments have been used in studying QOL. Michalos (1985) measured the perceived gap between achievement and aspiration in a variety of life experiences. Evans et al. (1985) used a lengthy series of True-False items built around interpersonal relations and activities that take place in leisure and organizational settings. In studying QOL among the developmentally disabled, Schalock and Keith (1984)

devised a 3-point scale (high to low) using specific objective indicators in the areas of environmental control, social interaction, and community utilization. For a group of severely disabled persons, Hill et al. (1984) used caregiver reports of time spent in specific leisure and social activities.

Researchers have used a wide variety of domains in evaluating QOL. The following are three examples of the types of domains that have been used:

1. Employment, Environment, Financial, Health, Mental Health, Nutrition, Social, and Transportation (Murrell et al., 1983).
2. General Well-being, Interpersonal Relations, Organizational Activity, Occupational Activity, and Leisure/Recreational Pursuits (Evans et al., 1985).
3. Marriage/Sex Life, Friendship/Leisure, Health/Fitness, Material Standard of Living, and Job Satisfaction (Heady et al., 1985).

Common themes that seem to run through most domain groups selected are social experiences, meaningful daily activity, community participation, and general sense of well-being. A number of studies use measures of both satisfaction and dissatisfaction, suggesting that both areas must be assessed to gain a true picture of QOL (Ferrans & Powers, 1985; Shin et al., 1983; Stones & Kozma, 1985).

One study is notable for its evaluation of not only various levels of satisfaction/dissatisfaction in selected domains, but also the importance of the domain to the person being evaluated. This yields the highest QOL scores for areas of high satisfaction/high importance and the lowest QOL scores for areas of high dissatisfaction/high importance (Ferrans & Powers, 1985). This factor of importance seems to be a logical variable to include in a QOL assessment, since it relates closely to individual differences that undoubtedly influence QOL perceptions.

In terms of validity and reliability, McNeil et al. (1986) suggest that multi-item scales are better than single item scales, since more rigorous psychometric evaluation is possible. Andrews & McKennell (1980) found that measures with 5 to 7 scale points give more valid results than 3-point scales. Many studies established reliability using test-retest and inter-rater methods, along with Chronbach's alpha to establish internal consistency (Ferrans & Powers, 1985; Schalock & Keith, 1984). Considerable experience with various instruments seems to confirm that self-report QOL scales are generally valid and correlate highly with observed behaviors (Deiner, 1984; Weinstein, 1982). Probably the most typical method of validity establishment with QOL measurements has been correlation of the instrument with a previously validated instrument that measures well-being or life satisfaction (McNeil et al., 1986; Stones & Kozma, 1985).

Clearly, the difficulty of measuring QOL has not deterred investigators from measuring it! While the results are varied and sometimes contradictory, the collective process of QOL research has been well served in the process. Researchers continue to seek better ways of evaluating the elusive construct that QOL has proven to be. Probably the biggest challenge lies in the fact that QOL means different things to different people. Nevertheless, it is a vital dimension of human experience that merits continued attention from researchers and practitioners alike.

### Ethical Concerns

Consideration of QOL issues for persons with disabilities has many ethical implications. Rosen (1986) suggests that, for some disabled persons, QOL may be optimal despite the absence of options available to those less severely impaired. This may require a somewhat different conception of QOL, one that is based on what can be appreciated, responded to, and integrated by the particular individual. To expect or demand more than this would be, in essence, unethical.

Schuessler and Fisher (1985) bring up a related ethical issue, questioning how far society should go in seeking to improve QOL for certain severely disabled individuals. While they present no pat solutions, they touch on an important area of concern for QOL study and thought.

Baroff (1986) effectively points out that contentment can be felt in both restrictive and non-restrictive settings as long as basic needs are being met. He cautions, though, that such contentment may be far from indicating genuine happiness with life. He suggests that policy makers and practitioners guard against using apparent contentment as a rationalization for custodial care as opposed to growth-promoting approaches to working with these individuals.

Many other ethical questions present themselves in thinking about evaluating QOL for persons with disabilities. Who decides what makes a person happy or unhappy when the person is not able to directly communicate that information at times? Is it appropriate to impose certain activities/pursuits on individuals in the name of improving their QOL? Is it ethically reasonable to judge a person as satisfied with their life when they have had little exposure to many life experiences?

There are no easy answers to these and similar questions, but clearly they must be addressed if QOL research among persons with disabilities is to maintain an ethical dimension.

## Conclusion

The interdisciplinary nature of QOL research, along with its integral ties to human development and social consciousness, make it an exciting and challenging field of inquiry. Beyond the diversity of definitions, the social-psychological correlates, the plethora of domains and indicators, and the knotty ethical questions, QOL emerges as a vital dimension of human existence that affects all persons individually and impacts society as a whole.

In addressing QOL issues for individuals with disabilities, much can be learned from the field of QOL research as a whole. In some ways, persons with disabilities and persons without disabilities are more alike than they are different. A great deal of the information presented in this review was drawn from research among the population at large. In practical terms, most of it can be applied or adapted in the more specific area of QOL among individuals with disabilities.

Some general inferences that may be drawn from the foregoing review are as follows:

1. Individuals with disabilities, like all persons, need to be involved in meaningful activity, socially supported, and high in self-regard in order to experience relatively positive QOL.
2. A realistic perspective of QOL acknowledges the role of individual differences as well as the impact of person-environment interactions.
3. QOL is highly subjective and its measurement must include subjective components.
4. Evaluative instruments for assessing QOL should be multi-dimensional and should include the opportunity to report both positive and negative experience.
5. Ethical issues related to QOL among the disabled must be kept in mind when measurement is undertaken and when strategies for improving QOL are devised.

Dell Orto (1982) has suggested that the role of rehabilitation and special education professionals is to help elevate the human experience to a level of choice rather than default. This notion may well be applied to all who work with disabled youth in transition to adulthood. QOL studies can provide valuable direction to programs and policies aimed at enhancing the opportunities for these students to attain a quality adult life.

References

- Abbey, A. & Andrews, F.M. (1985). Modeling the psychological determinants of life quality. Social Indicators Research, 16, 1-34.
- Andrews, F.M. & McKennell, A.C. (1980). Measures of self-reported well-being: Their affective, cognitive, and other components. Social Indicators Research, 8, 127-155.
- Andrews, F. & Withey, S. (1976). Social indicators of well-being. New York: Plenum Press.
- Baird, R.M. (1985). Meaning in life: Discovered or created? Journal of Religion and Health, 24(2), 117-124.
- Baroff, G.S. (1986). Maximal adaptive competency. Mental Retardation, 24(6), 367-368.
- Bortner, R. & Hultsch, D. (1970). A multivariate analysis of correlates of life satisfaction in adulthood. Journal of Gerontology, 25, 41-47.
- Brief, A.P. & Hollenbeck, J.R. (1985). Work and the quality of life. International Journal of Psychology, 20(2), 199-206.
- Brown, G.W. & Harris, T. (1978). The social origins of depression. New York: Free Press.
- Bubolz, M., Eicher, J., Evers, J., & Sontag, M. (1980). A human ecological approach to quality of life: Conceptual framework and results of a preliminary study. Social Indicators Research, 7, 103-116.
- Burckhardt, C.S. (1985). The impact of arthritis on quality of life. Nursing Research, 34(1), 11-16.
- Campbell, A. (1981). The sense of well-being in America. New York: McGraw-Hill.
- Campbell, A., Converse, P.E., & Rodgers, W.L. (1976). The quality of American life. New York: Sage.
- Crandall, J. & Putman, E. (1980). Relations between measures of social interest and psychological well-being. Journal of Individual Psychology, 36, 156-168.

- Dalkey, N. & Rourke, D. (1973). The delphi procedure and rating quality of life factors. In The quality of life concept. Washington, D.C.: Environmental Protection Agency.
- Dell Orto, A.E. (1982). Rehabilitation: Its bright past and brilliant future. Rehabilitation Literature, 43, 358-359.
- Diener, E. (1984). Subjective well-being. Psychological Bulletin, 95, 542-575.
- Evans, D.R., Burns, J.E., Robinson, W.E., & Garrett, O.J. (1985). The quality of life questionnaire: A multidimensional measure. American Journal of Community Psychology, 13(3), 305-322.
- Ferrans, C.E. & Powers, M.J. (1985). Quality of life index: Development and psychometric properties. Advances in Nursing Science, 8(1), 15-24.
- Gecas, V. (1982). The self-concept. Annual Review of Sociology, 8, 1-33.
- George, L. & Bearon, L. (1980). Quality of life in older persons. New York: Human Sciences Press.
- Harris, L. & Associates. (1985). Harris poll on the disabled. New York: International Center for the Disabled.
- Heady, B., Holmstrom, E., & Wearing, A. (1985). Models of well-being and ill-being. Social Indicators Research, 17, 211-234.
- Henderson, S., Byrne, D.G., & Duncan-Jones, P. (1981). Neurosis and the social environment. Sydney: Academic Press.
- Kazak, A. & Linney, J. (1983). Stress, coping, and life change in the single-parent family. American Journal of Community Psychology, 11(2), 207-220.
- Landesman, S. (1986). Quality of life and personal life satisfaction: Definition and measurement issues. Mental Retardation, 24(3), 141-143.
- Margalit, M. & Cassel-Seidenman, R. (1987). Life satisfaction and sense of coherence among young adults with cerebral palsy. Career Development for Exceptional Individuals, 10, 42-50.
- Mastekaasa, A. & Moum, T. (1984). The perceived quality of life in Norway: Regional variations and contextual effects. Social Indicators Research, 14, 385-419.

- McNeil, J.K., Stones, M.J., & Kozma, A. (1986). Subjective well-being in later life: Issues concerning measurement and prediction. Social Indicators Research, 18, 35-70.
- Michalos, A.C. (1985). Multiple discrepancies theory (MDT). Social Indicators Research; 16, 347-413.
- Milbraith, L.W. (1982). A conceptualization and research strategy for the study of ecological aspects of the quality of life. Social Indicators Research, 10, 133-157.
- Møller, V. & Schlemmer, L. (1983). Quality of life in South Korea: Towards an instrument for the assessment of quality of life and basic needs. Social Indicators Research, 12, 225-279.
- Murrell, S.A., Schulte, P.J., Hutchins, G.L., & Brockway, J.M. (1983). Quality of life and patterns of unmet need for resource decisions. American Journal of Community Psychology, 11(1), 25-39.
- O'Connor, P. & Brown, G.W. (1984). Supportive relationships: Fact or fancy? Journal of Social and Interpersonal Relationships, 1, 159-175.
- Pearlin, L., Lieberman, M., Menaghan, E., & Mullan, J. (1981). The stress process. Journal of Health and Social Behavior, 22, 337-356.
- Reich, J.W. & Zautra, A.J. (1983). Demands and desires in daily life: Some influences on well-being. American Journal of Community Psychology, 11(1), 41-58.
- Rice, R.W. (1984). Organizational work and the overall quality of life. Applied Social Psychology Annual, 5, 155-178.
- Rosen, M. (1986). Quality of life for persons with mental retardation: A question of entitlement. Mental Retardation, 24(6), 365-366.
- Russell, J.A. & Ward, W. (1982). Environmental psychology. Annual Review of Psychology; 33, 651-688.
- Sarason, I.G., Levin, H.M., Basham, R.B., & Sarason, B.R. (1983). Assessing social support: The social support questionnaire. Journal of Personality and Social Psychology, 44, 127-139.
- Schalock, R.L. & Keith, K.D. (1984). DD client and staff variables influencing outcomes of service delivery: Present and future models. Lincoln: Developmental Disabilities Planning Council, Nebraska Dept. of Health.

- Schalock, R.L. & Lilley, M.A. (1986). Placement from community-based mental retardation programs: How well do clients do after 8 to 10 years? American Journal of Mental Deficiency, 90(6), 669-676.
- Schneider, M. (1976). The "quality of life" and social indicators research. Public Administration Review, 36, 297-305.
- Schuessler, K.F. & Fisher, G.A. (1985) Quality of life research and sociology. Annual Review of Sociology, 11, 129-149.
- Shin, D.C., Ahn, C.S., Kim, K.D., & Lee, H.K. (1983). Environmental effects on perceptions of life quality in Korea. Social Indicators Research, 12, 393-416.
- Stensman, R. (1985). Severely mobility-disabled people assess the quality of their lives. Scandinavian Journal of Rehabilitation Medicine, 17(2), 87-99.
- Stones, M.J. & Kozma, A. (1985). Structural relationships among happiness scales: A second order factorial study. Social Indicators Research, 17, 19-28.
- Taft, B. (1985). Self-esteem in later life: A nursing perspective. Advances in Nursing Science, 8(1), 77-84.
- Turnbull, A.P. & Turnbull, H.R. (1985). Developing independence. Journal of Adolescent Health Care, 6(2), 108-119.
- Weinberg, N. (1985). Physically disabled people assess the quality of their lives. Rehabilitation Literature, 45, 12-15.
- Weinstein, L. (1982). Positive contrast as due to happiness. Bulletin of the Psychonomic Society, 19, 97-98.
- Zautra, A.J. (1983). Social resources and the quality of life. American Journal of Community Psychology, 11(3), 275-290.

Part II  
FIELD STUDY REPORT

Field interviews were conducted to augment the literature review with a more personalized perspective on the meaning of quality adult life for individuals with disabilities.

Interviews were conducted informally with small groups of disabled adults. Forty-five persons, ranging in age from 20 to 50, were interviewed. Most of the individuals were young adults in their twenties or early thirties. Disabilities included cerebral palsy, head trauma, deaf and hearing impaired, blind and visually impaired, learning disabled, developmentally disabled, and emotionally disturbed. A number of individuals were multi-handicapped. Within this wide range of disabilities, some persons obviously were more perceptive and/or articulate than others. However, every effort was made to determine concerns, priorities, and specific areas of positive or negative feelings.

On several occasions, a teacher, interpreter, or agency representative was present during the interviews. Most sessions lasted approximately one and one half hours. All sessions were conducted jointly by the project director and the project consultant. In all cases the respondents were enthusiastic about the Quality of Life (QOL) project and eager to share their opinions and feelings.

Eight domains were explored during the interviews. These were: Environment, Employment/Occupation, Education/Training, Health, Community Utilization, Personal Management, Leisure/Recreation, and Interpersonal Relations. These domains evolved as part of the project's working draft of a prototypical survey instrument to assess QOL of persons with disabilities.

Despite specific concerns unique to each disability group, such as accessibility/transportation for persons with cerebral palsy and communication obstacles for deaf/hearing impaired individuals, three domains were mentioned repeatedly as areas needing improvement or contributing to negative experiences/feelings. These three domains were:

1. Interpersonal Relations, i.e. getting along with others, friendships, opportunities to share activities/feelings.
2. Environment, i.e. living situation, neighborhood, privacy, opportunities for independence within the home setting.
3. Community Utilization, i.e. transportation, agency services.

An in-depth look at the types of concerns that surfaced around these three domains provides excellent insight into much of what is at the heart of quality adult life for persons with disabilities. While each respondent expressed positive life experience in a number of areas, the focus on these areas of concern predominated the interviews.

For all groups, social/interpersonal concerns were primary and were verbalized in a variety of ways. Some typical comments were:

- "I have lots of friends but no close relationships."
- "I don't know how to get friends."
- "There is no one I can really talk to."
- "The only people I see besides my family are at school (work, service agency, etc.)."
- "I don't get along with my roommate."
- "I'd like to be able to interact with non-disabled."
- "I wish I had one good friend I could tell anything to."
- "It's assumed by others that we will never have a sex life."
- "My dad laughed when I said I might give him grandchildren."
- "I don't know how to pursue an intimate relationship."
- "I'm lonely."

Clearly, social relationships are not a luxury for disabled people any more than they are for non-disabled. They are essential. People need to be able to make friends and get along with others, to have someone in whom to confide, in order to lead satisfying lives. Successful transition includes competent social skills and the opportunities to practice and utilize them.

The second most frequently mentioned domain involved environmental issues. These included present living arrangements (where and with whom), privacy, neighbors and neighborhood, and opportunities to plan daily meals and schedules. Independence, or the process of becoming independent, was definitely a positive QOL indicator, and the lack of it was a negative indicator for almost all adults interviewed. For those lacking the degree of independence they desired, a greater sense of being on their own was always a goal. Common responses were:

- "I worry about getting an attendant if something happens to my mom."
- "Our neighborhood is not good. We have to call the police a lot of times."
- "My kitchen was not designed for a wheelchair, so I can't cook for myself."
- "It's hard to find a place that will rent to a disabled person."
- "I'd like to run my own life."
- "I've been waiting to get into the independent living program for a long time."

Obviously, self-sufficiency is highly desirable and, when beyond one's grasp, enormously frustrating. Positive self-image is, among other things, integrally tied to the ability to manage one's own life.

Community utilization was the third most frequently mentioned area generating QOL concerns for the interviewees. Within this domain, transportation was a dominant issue. Many individuals with disabilities are limited in their ability to get around freely, and this can be a daily dissatisfier in some cases. Typical responses included:

- "Sometimes the wheelchair bus goes right on by me."
- "I can't go anywhere without planning a week in advance!"
- "Services are not as good as they sound."
- "Transportation is my major problem, especially for recreation or spontaneous events."
- "I'd like to be able to spend my energy on other things besides getting around."
- "I hate always having to depend on friends or family to take me places."

Other areas of concern regarding community utilization included accessing the services of agencies, participating in cultural events or political activities, and simply knowing how to get more involved in community life.

Across disability groups, many voices were raised in frustration over the lack of public awareness, as well as community attitudes and prejudices towards people with disabilities. At least one individual in every group reported an experience with some type of discrimination in a major daily activity. Community awareness and prejudicial attitudes were also indicated when the interviewees were asked what they would like to change in their lives.

For interviewees who had occupations and some degree of independence, it was clear that their sense of self-worth was enhanced, especially for those who were living on their own. In general, the respondents rated their overall QOL as fair to very good. Most of them suggested that they were not so much unhappy as they were frustrated with certain aspects of the three domains discussed previously.

Although limited in scope, this field study provides some excellent guidelines for assessing QOL among persons with disabilities. In many respects, the areas that are important to these disabled adults are no different than aspects of life that are important to all persons -- the opportunity to take care of oneself, the support and nurturance of close relationships, and a sense of belonging in the community. These things provide identity and value for disabled and non-disabled alike. Their achievement is a good part of what makes successful transition the key to a life of quality.

Part III

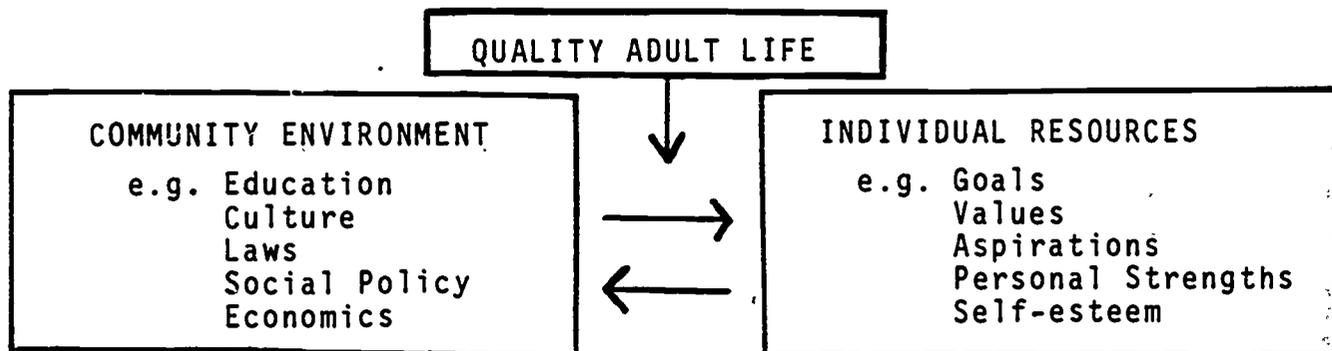
A DEFINITION OF QUALITY ADULT LIFE

Based on information gathered from the literature review and the field study interviews, a definition of quality adult life has been formulated. It is presented below, along with a brief commentary and a corresponding diagram that visually depicts the definition.

Definition: A QUALITY ADULT LIFE IS ONE IN WHICH COMMUNITY ENVIRONMENT AND INDIVIDUAL RESOURCES ARE ABLE TO INTERACT IN WAYS THAT ENHANCE THE FULLEST POSSIBLE HUMAN DEVELOPMENT OF THE PERSON.

Commentary: This definition is, in effect, a macro-synthesis of available information on quality of life. It represents an attempt to transcend the multiplicity of domains and move to a broader level where any domain deemed appropriate can be incorporated into the model. Grounded in a social-ecological framework, this definition acknowledges both the individual nature of life quality experience and the function of the community as the life arena of the individual.

As the diagram indicates, the individual component includes all that a person brings to life. The community component includes the social structure and processes that may not only meet the individual's needs but also contribute to the development of many of the individual's resources. It is primarily in the successful interplay between the two components that a quality adult life takes shape and grows.



# **Quality of Life for Individuals With Disabilities:**

Quality of Life Survey

**Education Transition Center**

**Program, Curriculum, and Training Unit  
California State Department of Education  
Special Education Division  
Sacramento, California**

## INTRODUCTION

This instrument was developed for use with disabled persons, primarily young persons in transition to adulthood. However, it is appropriate for use with other groups as well.

Pages 2 through 5 constitute the instrument itself. Page 1 is a brief form for gathering some basic demographic information. These five pages constitute the entire instrument as it appears to the respondent.

Scoring instructions follow page 5. This survey was developed as a prototypical instrument; hence, no validity/reliability information or norms are yet available. The domains assessed and the specific items were developed through an information synthesis process that was part of project a.1.4.

## ADMINISTRATION

The survey may be administered in person, by telephone, or by having the respondent read and complete the information. In many cases, depending upon type of disability, reading by the respondent is not feasible. In most cases, it is appropriate for the rater to clarify the meaning of an item if the respondent does not seem to understand it clearly.

Administration of the instrument usually takes about 20 minutes, although the time may vary considerably depending upon the respondent. Scoring is a relatively simple process as well.

In addition to providing a somewhat global picture of how an individual is feeling about his/her life, the instrument allows for isolation of specific domains for program planning or counseling purposes.

QUALITY OF LIFE SURVEY

\_\_\_\_\_  
(Date)

Respondent's Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Birthdate: \_\_\_\_\_ Sex: F M

Current Occupation: \_\_\_\_\_

If Student, School of Attendance: \_\_\_\_\_

If Employed, Location: \_\_\_\_\_

Duties: \_\_\_\_\_

Length of Employment: \_\_\_\_\_

Previous Employment Experience: \_\_\_\_\_

- Currently Living:
- a. With parent/guardian
  - b. In foster care
  - c. In residential care
  - d. In group home
  - e. Independently
  - f. Other : \_\_\_\_\_

Disability (if applicable): \_\_\_\_\_

Hobbies/Leisure Activities: \_\_\_\_\_

QUALITY OF LIFE SURVEY

Circle one number for each item.

Never 1	Rarely 2	Sometimes 3	Often 4	Almost Always 5
------------	-------------	----------------	------------	-----------------------

ENVIRONMENT (Env)

I feel good about my present living arrangements (where, who, etc.).	1	2	3	4	5
I plan my own meal times.	1	2	3	4	5
My neighbors are friendly to me.	1	2	3	4	5
I choose my own sleeping schedule.	1	2	3	4	5
I have time and space to be alone at home if I want.	1	2	3	4	5

EMPLOYMENT/OCCUPATION (EmpOcc) (skip if N/A)

I like talking to others about my job.	1	2	3	4	5
My supervisor lets me know when s/he is pleased with my work.	1	2	3	4	5
I enjoy my work.	1	2	3	4	5
I choose how to spend my break time and lunch time.	1	2	3	4	5
My coworkers treat me well.	1	2	3	4	5

EDUCATION/TRAINING (EdTrg)

When I am in school I make my own decisions about what classes to take.	1	2	3	4	5
I have enjoyed the training and education I have had so far.	1	2	3	4	5
Teachers and other students are (or were) friendly to me in school.	1	2	3	4	5

1	2	3	4	5
Never	Rarely	Some- times	Often	Almost Always

I am (or was) satisfied with the educational or vocational guidance provided to me.

1 2 3 4 5

If I wanted or needed more education or job training, I would know where to find out about it.

1 2 3 4 5

HEALTH (Hlth)

I am satisfied with my physical health.

1 2 3 4 5

I feel that I am able to handle the stress in my life.

1 2 3 4 5

I go to the doctor and dentist regularly for check-ups.

1 2 3 4 5

I make my own appointments to visit the doctor or dentist.

1 2 3 4 5

If something is really bothering me, I would consider going to see a counselor.

1 2 3 4 5

COMMUNITY UTILIZATION (CommUt)

If I want to attend a community event, I can find a way to get there.

1 2 3 4 5

I participate in clubs or other organizations in my community.

1 2 3 4 5

If something needs fixing, I know how to get repair services.

1 2 3 4 5

I am the one who decides what events I attend in the community.

1 2 3 4 5

I am satisfied with the amount of time I am able to spend doing things away from home.

1 2 3 4 5

PERSONAL MANAGEMENT (PrsMgt)

Never 1	Rarely 2	Some- times 3	Often 4	Almost Always 5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

I am satisfied with my ability to organize my time.

I manage my own money.

When I need transportation, I arrange for it myself.

I choose the clothes I wear.

Decisions I have made about my life have turned out well.

LEISURE/RECREATION (LeiRec)

I spend some time each week doing recreational activities.

Leisure/recreation facilities that meet my needs are available in my town.

I am happy with the ways I spend my spare time.

I have enough money to go on an outing or take a vacation from time to time.

I am satisfied with the amount of leisure time I have available.

INTERPERSONAL RELATIONS (IntRel)

I get along well with other people.

When I want to share an activity, I can find someone to go with me.

I am satisfied with the number of friends I have.

I am comfortable with the way I handle myself when things aren't going well with someone.

There is someone close to me with whom I share my most important thoughts and feelings.

1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

WHICH OF THE FOLLOWING THINGS ARE YOU WORRIED ABOUT LATELY?  
(Circle the numbers.)

1. Getting through school or finishing my training program.
2. Treatment I receive from community agencies.
3. My physical health.
4. Housing arrangements.
5. Relationships with parents or other family members.
6. Amount of time I have for recreation.
7. Finding the right job training.
8. Getting along with neighbors.
9. My ability to make good decisions.
10. Having one or more close friends.
11. Getting things done that I need to do.
12. Feeling lonely or isolated from others.
13. Kind of work I am doing.
14. Being able to do the leisure activities I enjoy.
15. Having a spouse or life partner.
16. Ability to get transportation easily and conveniently.
17. Financial situation.
18. Amount of stress in my life.
19. Getting a reliable person to help me with my self-care needs.
20. Problems with drugs/alcohol.

IN GENERAL, HOW HAPPY ARE YOU WITH THE WAY YOUR LIFE  
IS GOING THESE DAYS?

(circle one)

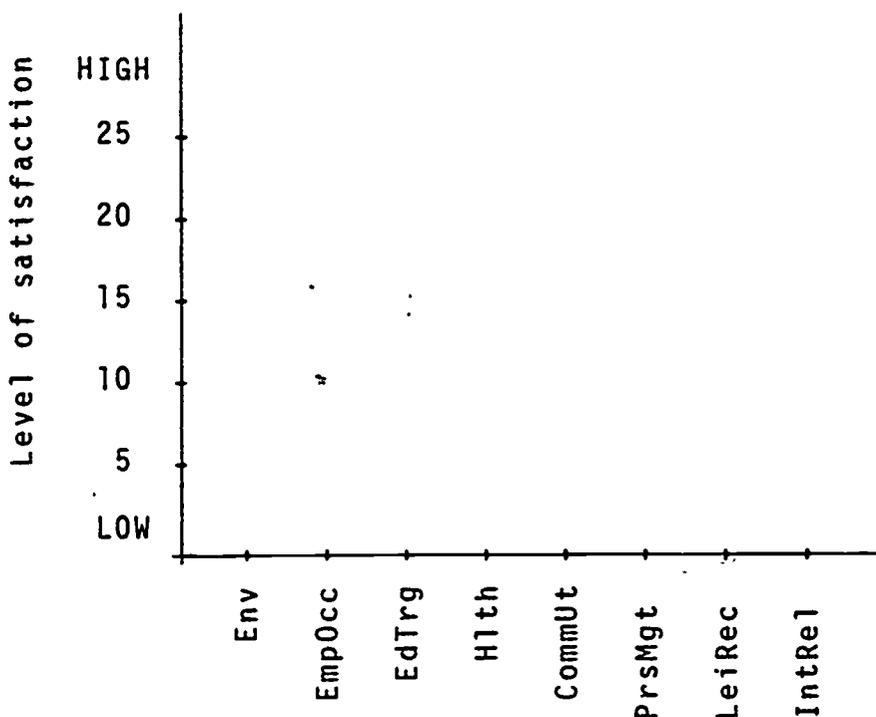
- 1 Not at all happy
- 2 Not too happy
- 3 Happy now and then
- 4 Fairly happy
- 5 Extremely happy

Scoring Sheet  
for  
Quality of Life Survey

Respondent's Name: \_\_\_\_\_ Date: \_\_\_\_\_

1. Sum the numbers circled for each domain, then plot the totals on the graph.

<u>Domain</u>	<u>Total</u>
Env	_____
EmpOcc	_____
EdTrg	_____
Hlth	_____
CommUt	_____
PrsMgt	_____
LeiRec	_____
IntRel	_____



This gives a graphic presentation of satisfaction levels comparatively across the 8 domains.

2. To get a global score, obtain a grand total of the sums from #1 and divide by the number of items to which the individual has responded (likely 40 unless unemployed).

GLOBAL SCORE: \_\_\_\_\_

3. How closely does the global score from #2 come to the number circled on the last item of the instrument? If the two numbers are fairly close, there is probably substantial reliability among the respondent's answers. If not... INVESTIGATE!!

4. The 20-item list of possible worries or concerns may also be used, like the global question, to corroborate the respondent's answers. Listed below are the numbers of the "worry" items that correspond to each of the domains of the survey. For each domain, list how many items were circled. Then compare these figures to the graph. Are the LOW areas of the graph the same areas with the most "worry" items circled? If so, there is some corroboration. If not... (of course... INVESTIGATE!!)

<u>Domain</u>	<u>Item Nos. from "Worry" List</u>	<u>How Many Did Respondent Circle?</u>
Env	4,8	_____
EmpOcc	7,13	_____
EdTrg	1,7	_____
Hlth	3, 18, 20	_____
CommUt	2,16	_____
PrsMgt	9,11,17,19	_____
LeiRec	6,14	_____
IntRel	5,10,12,15	_____

(note: #7 pertains to two domains)